

Procreation, Power, and Personal Autonomy: Feminist Reflections

Chapter 8

Family Politics and Personal Autonomy: At the Junction of Biological and Social Connection

My intent in this chapter is to consider the pulls and tugs of changing family patterns. I focus on the bearing of recent and forthcoming developments in genetic diagnosis on biological dimensions of family relationships and the conceptual framework within which family members shape their discrete identities and seek autonomous self-determination. I first consider the emergence of new family norms that diminish the significance of biological connection. Then I turn to the influence of genetics on family relations, focusing particularly on how genetic-related decision-making affects both significant social relationships and the self-understandings of individual family members. I mention major respects in which women's lives are likely to be more disturbed by genetic knowledge than men's. I argue that the dominant individualistic understanding of autonomy is poorly suited for resolution of quandaries where genetic information needs to be taken into account. I offer in its place a relational conception of autonomy and show how this alternative conception brings into central focus issues that the standard conception relegates to the margins. Then I consider how access to information bearing on relations with others can impede or promote autonomy. Next, I turn to the responsibilities this vulnerability imposes on medical providers who advise women and their families of their options. I emphasize the power of genetic knowledge to thwart or advance autonomy depending on how it is embedded in clinical relationships.

Changing Family Norms

Family is a multiple, contested, and variable concept. Because there is no single set of characteristics shared by all relationships that count as “family” in all cultures and traditions, philosophers sometimes speak of family as a family resemblance concept (Card 1996). For family relationships share a cluster of overlapping features. Boundaries demarcating networks of family relations fluctuate across social classes, cultural customs, ethnic traditions, and historic eras. Some maintain, however, that in recent years variability in family patterns has accelerated. A number of observations support this view.

Technological intervention, cross-cultural adoption, escalation of divorce and remarriage, and a spiraling global economy all contribute to changes in family patterns. Though the network of social relations that counts as family still overlaps blood links, social and cultural features of relationship often overshadow biological ties. Transnational institutions are having a growing impact on family structures and norms. Alison Jaggar points to relations between the growing dominance of the global market and the

loss of opportunity to meet family needs through local markets.¹ This is not only a problem for developing areas of the world but affects advanced industrialized economies too. For in virtually all areas of the world women suffer disproportionately from persistent male-biases in the workforce. Not only is women's comparatively cheap labor power exploited, but increasing privatization of national economies diminishes women's and children's access to social benefits. In poorer countries women are often conscripted to work overseas as domestics or sex workers, breaking up their family units and intensifying gulfs between affluent and impoverished peoples.

So social and economic class are major factors in changing family forms. In many cultures and disadvantaged communities in the West, biological relationship is often a comparatively minor consideration. Families tend to be functional units that are shaped more by mutual support and survival than by kinship ties.² In the West, as rates of divorce and remarriage escalate among all social classes, "blended" families become more common. Some divorced spouses maintain connection with kin of their former partner, but many sever these relationships when a marriage dissolves. The new partner of the custodial parent often acquires step-parent status and the biologically unrelated children may see themselves as brothers, sisters, or cousins. Among the middle classes, these perceptions vary from family to family. Adoption, increasing use of gamete donors, contract pregnancy, single parent families, and single-sexed families all contribute to a more extended notion of what may count as family.

These new social arrangements support a conception of family that includes people with whom one has no ties either biologically or through marriage. For the advent of technically innovative reproductive arrangements makes it far more likely that people will be biologically linked to those with whom they have no affective ties and intimately bound to those with whom they have no biological ties.³

Feminists who view inter-generational biological links through a socio-political lens often applaud such reconfigurations of family. Biological families are reactionary and repressive, some insist,

1. I owe this point to Alison Jaggar's invigorating paper at the 2006 Feminist Ethics and Social Theory conference. She cites Thomas Pogge's 2002 book, specifically, to illustrate the dominant emphasis on family as a local institution.

2. Functional conceptions of families are often contrasted to essentialist ones. Feminists have long debated the comparative merits of these contrasting conceptions and used the distinction to critique the views of others. On this distinction see Barrett and Phillips 1992. On feminist debates see Nicholson 1990 and Fraser and Nicholson on Nancy Chodorow's implicit adoption of functionalism in Trebilcock 1984.

3. The policies of many countries discourage modes of procreation that foster relationships that can't be subsumed under the nuclear family norm. For instance, many countries that regulate donor insemination still shroud the practice in secrecy and refuse to grant these children access to identifying information about donors that is comparable to the information provided to adoptees. Most, however, now make some effort to maintain records that include genetic information about the donor and in some countries these records include identifying information. Sweden, Austria, and Great Britain now permit access to identity and several other countries are considering opening records to 18 year olds on request.

replicating and reproducing from other social domains hierarchical gender relations that reinforce the continuing subjugation of women, sanction violence and abuse, and inhibit the development of an autonomous sense of self.⁴ Few today would defend Shulamith Firestone's view that fetuses should be gestated in laboratories and assigned to willing parents randomly at birth (1971). Yet Firestone's advocacy of a conception of family that is not imposed, but voluntary has held its appeal throughout the intervening years.⁵ Some feminists today are pressing for recognition of alternative family arrangements that would reconstitute family in nonbiological ways and assign parental rights on the basis of an adult's nurturing relationship to a child.⁶ As a measure to resolve child custody disputes, such proposals for reconfiguring parental duties have undoubted merit, but as an overall child-rearing policy, they are problematic.

Several considerations cast doubt on their feasibility. First, emerging new family arrangements are sporadic and unreliable. We cannot know yet whether they are likely to fulfill the socially useful functions that social families joined by biological links ideally provide: a context for personal intimacy and well-being and the stability and continuity of care necessary for an optimally secure childrearing environment. Nurturing is not the sole component of adequate child rearing. It should not overshadow other stability-maximizing considerations.

Second, developments in embryology and genetics that facilitate assisted reproduction and identification of genetic disorders are escalating rapidly. Though IVF and related techniques could be used in ways that weaken biological connection, the primary objective of most people who utilize these technologies is to produce a child who is biologically related to at least one of the parents-to-be. As identification of genetic disorders escalates, the significance of biological connection intensifies. Issues surrounding newly developing genetic knowledge vividly illustrate the extent to which biological grounding is embedded in social institutions, penetrates individual self-perceptions, and perpetuates (often exacerbating) social injustices. The specter of genetic disease compels reappraisal of both the biological dimensions of family relationships and the conceptual framework within which family members shape their discrete identities and seek autonomous self-determination.

4. Others point out that emphasis on blood ties is not biologically given but culturally and historically specific. Note, for instance, F. Edholm, "The Unnatural Family," 1982.

5. For elaboration on this point see Asch in Wolf 1996: 341-342.

6. This proposal pops up principally within the context of contested custody disputes, but some would like to see it applied more broadly. See, for instance, Mahoney 1995. For a more general rights-based framework for family relations that does not refer to the nurturing relationship specifically, see Minow and Shanley 1996.

Needed is a public policy supporting an alternative framework that, instead of idealizing traditional families, reflects actual human practices. It would envision families within their societal context and respect the autonomy of individual family members as agents fundamentally involved in relationships that are not of their own making. It would recognize social and economic burdens imposed on families by reproductive and genetic innovations and institute appropriate measures to remedy injustices to social groups. It would acknowledge the interconnectedness of human communities across barriers of gender, race, culture, and economy. Borrowing from a metaphor of Patricia Williams, instead of viewing groups of individuals on the model of a jar of marbles, one of which can be removed without affecting the others, it would adopt the model of a jar of soap bubbles: none can be pricked without altering the identity of the others (1995, 86).⁷ In the balance of this chapter I consider relations between genetic ties and family relations that support the case for such a framework.⁸

Family Burdens and the New Genetics

One way to advance these goals, it's been suggested, is through ethically astute public education programs involving medical practitioners and potential patients. With this end in mind, I looked into genetic education projects and inadvertently discovered the complexities of this approach and the tendency to skew alternatives, stressing only the radical potential of new techniques and bypassing more moderate options. One project, commissioned by a leading sponsor of genetic research, dramatically demonstrates how individual identity is bound up with relations to biologically linked kin. However, the project perpetuated an overly individualistic account of autonomy that threatened close interpersonal relationships, thus endangering both individual self-determination and family well-being.⁹

The focal point of the project was a play called "The Gift," expressly written to elicit audience response to genetic selection techniques. The action focuses around a sprightly athletic sixteen year old girl who develops early symptoms of Friedreich's ataxia, an autosomal recessive disorder that affects the central nervous system and leads to progressive deterioration of coordination and loss of muscle control. Her mother reproaches herself for being an unwitting carrier.¹⁰ Her vibrantly healthy brother resolves

7. I adapt these models from Ruth Groenhout's use of them in her 2004 book.

8. I am very much indebted to Virginia Held whose reconfiguration of moral theory has stimulated the thinking of many feminists. Her critique of the term "applied ethics," underlies much of my own reflection on this mislabeled (and often maligned) enterprise. For a brief recent summary of her perspective see her "Taking oneself, but not too" in Alcoff, ed. 2003, particularly at 53-54.

9. The project was sponsored by the Wellcome Centre for Medical Science, an initiative of the United Kingdom's largest medical research charity, the Wellcome Trust. The play was written by Nicola Baldwin. Further information is available from the Wellcome Centre, 210 Euston Road, London NW1 2BE.

10. Since it is a recessive gene, it's not clear why only she feels guilty. The child cannot be affected unless both parents are carriers.

not to risk transmitting the disorder to his own children. But this determination does not deter him from reproducing. As the play shifts to the future, reproductive options have expanded rapidly. Opportunities abound to select the characteristics of one's offspring, and the brother of the affected girl seizes the chance. By 2025, his own son Robert has reached the age when his affected aunt's symptoms first appeared. He learns that his own conception was preceded by preimplantation diagnosis. Embryos that carried the Friedreich's ataxia gene were discarded. Also, following his father's directive, the "best" embryo of the lot, a male with a genetic predisposition for athletic prowess, was plucked out for transfer to his mother's womb (overruling her own reservations).¹¹ Robert reacts angrily to the disclosure. He protests that both his sexual identity and his athletic abilities were "chosen" for him, so he is a product of his father's ambition, loveable only insofar as he lives up to pre-programmed expectations.

Following the play, the audience was invited to act as an ethics committee to frame genetic policy. A discussion facilitator offered several options: when such techniques become feasible should they be available to individual parents? Which? All alternatives? Or only those that aim to avoid suffering? Should the state regulate to prohibit options that would select embryos by sex or aim to enhance the aptitudes of otherwise "normal" people? Ignored by the facilitator were the more subtle ambiguities suggested in the play's title. Who is the beneficiary of this "gift"? Should human choice be trusted to supplant chance in the selection of genetic progeny? Why should it matter to future children whether their genetic traits are left to chance or deliberately selected by their parents? Does the father's intervention seriously limit his son's capacity for autonomous self-determination? Does the public have a stake in the uses to which such newly emerging technologies are put? This complicated tangle of moral, social, and metaphysical issues was reduced to two dichotomously opposed alternatives: either the state regulates options selectively or individual parents freely choose for their offspring whatever characteristics the parent most desires.

Surely, there is urgent need for popular education that increases public awareness about the impact of genetic research. An educated public is vital to any effort to anchor public policy in democratic consensus. But this project stacks the deck. Though the play invited myriad interpretations, those offered to the "ethics committee" were tailored around an illusory conception of autonomy that idealizes the individual decision-maker and abstracts options from both context and consequences. It reduced a host of complexities to a single message: the new genetics will be problem-free if affected embryos are eliminated.

Within the play the father's unilateral exercise of autonomy preempts both his wife's and their future son's autonomy capacities. The son's reaction upon disclosure of his origins points to a troubling feature of genetic enhancement techniques that is not present where genetic modification aims only to

11. A number of philosophers have advocated this kind of exercise of parental discretion. The view that individual parents should be left free to make such decisions has been forcefully argued by Singer and Wells 1984, Glover 1984, Harris 1992, and Robertson in a number of his publications. See also Buchanan 2000. By implication, my critique extends to all views that presume individual parents should have extensive authority to select the genetic composition of their offspring.

circumvent disabling disease. The imprint of the father's preferences on the son's genetic constitution creates an expectation that the son live up to the "superior" potential the father intended for him. Had his genetic makeup been left to chance, the measure of his accomplishment would give greater scope to his own self-imposed standards. True, all parents make decisions about the children's talents and capabilities. All children during their formative years are subject to the environmental pressures of family and society. But as adults they have opportunity to critically reappraise those pressures and break away from features acquired in the course of his socialization.¹² The range of choices is also circumscribed by cultural limitations. The ability to speak multiple languages, for instance, is restricted by the selection of a native language. Such limitations, however, are preconditions for any mode of rearing. But the imprint of a parent's choice on an offspring's genetic constitution is unlike these other limitations; it is not arbitrary but deliberate. It imposes a fixed standard, less open to modification or repudiation.¹³ In this instance the father's autonomous choice is purchased at the expense of his son's opportunities to be author of his own life.¹⁴

Relationships among the characters lend themselves to multiple interpretations beyond those actually offered. For as is often the case, members of this family were deeply interdependent and their destinies were tied to invisible others who shaped or facilitated their preferences. Explicit recognition of this influence, however, would require a vision of family dynamics open to the psychological, material, and social constraints that shape its members' options. A discourse more sensitive to such complexity would afford a firmer grasp of moral options open to people and a more relational understanding of their identities, capacities for self-direction, and responsibilities to one another.

How Genetic Decision-making Affects Significant Social Relationships

"The Gift" fails to accomplish its educational goals because it oversimplifies alternatives and conveys the false expectation that the most troubling problems raised by the new genetics can be solved by eradicating embryos that carry severe genetic disorders. To understand why elimination of all affected embryos is neither possible nor necessarily desirable, it is important to take into account the social and institutional context within which genetic alternatives are framed and concerns about potential societal discrimination among populations judged to be "at risk" for genetic disorders. No simple formula can solve the problems that the new genetics raises or shortcut the task of rethinking and renegotiating our

12. On this issue note Jurgen Habermas's interesting article and comments on it in the *American Philosophical Association Newsletter*, 2003, 3:1, 145150.

13. The self-identity problems noted here would be intensified still further if efforts to clone humans were to succeed.

14. LP: It's not clear to me that this is the only reasonable interpretation of the situation. Might offspring not see the parent's choice as a capacity that they can use if they so wish, but not something that imposes any obligation to develop or use.

relation to this new knowledge. I will argue that a comprehensive understanding will require integrating a relational understanding of personal autonomy.

The need for such a perspective is particularly striking when a woman who is genetically "at risk" becomes pregnant. A spouse may never have considered the full impact of marriage to the carrier of a genetic condition until the couple considers children. Dominant carriers are bound to know about affected people within their own families, but recessive carriers may well have no advance knowledge of the genetic anomaly. Everyone is a carrier for several recessive conditions, but offspring can acquire such a condition only when two carriers mate.¹⁵ Often, as in "The Gift," parents learn about their carrier status only after diagnosis of their own child. Occasionally, their status is detected through population screening programs or when another relative gives birth to an affected child. Sometimes a couple planning a family undergoes genetic diagnosis for one condition and unexpectedly learns that they are both carriers for another disorder they knew nothing about. Most often, though, a woman is already pregnant before genetic testing for carrier status is recommended to her. Then her options are already very limited. Pregnancy imposes pressures on decision-making that would not exist under less constraining conditions. If the couple is willing to consider termination, they may have to decide very quickly. Seldom do they know much about the particular genetic condition, the prognosis for the child, social support services, or how their own lives will be affected if they have a disabled child. Test results compound these uncertainties since their degree of accuracy varies. Some are so imprecise that false positive and/or false negative results are common. So suddenly a happy, untroubled pregnancy is transformed into a stressful experience, upsetting everyone's prior expectations.

Trained and experienced counselors will tell people who consider testing for a severe dominant disorder that regardless of the results, their futures will be changed. The news won't be all good or all bad for anyone (Stanford, 1994:14). Learning that one belongs to an affected family is bound to have a profound impact on all family members both individually and collectively. The circumstances of testing magnify this effect. First, for many genetic conditions the judgment that one is "high risk" involves pooling information among those who share the same blood line. So psychological, familial, and social complexities will compound the medical risks. The autonomy of individuals who would prefer not to know but cannot resist pressure by other family members will be compromised.

In instances where a family is evaluated to find the most likely transplant donor or where linkage studies are done to assess risk for a genetic condition, blood studies may also reveal misattributed paternity, such that the social father is not the biological father as family members believed. Where relationship between the parents is ongoing, the practitioner faces a burdensome quandary. Who should be informed? Should unwelcome information be imposed on people? When this information comes to light in the process of screening for a suitable organ or tissue donor, the medical unit might establish a de facto policy to disclose only information pertinent to the search for a compatible donor. If a family

15. Common autosomal recessive disorders include cystic fibrosis, sickle cell disease, thalassemia, and Tay-Sachs disease. Among X-linked recessive disorders are hemophilia, Duchenne muscular dystrophy, and fragile X syndrome.

member has already told the transplant team that he will contribute a blood sample to provide a more complete family profile but is unwilling to donate, the sample would be used only to establish linkage and then set aside in the continuing search for a suitable donor. But where family linkage studies are undertaken to determine carrier status for a genetic condition this dodge won't work. So many idiosyncratic aspects of the family situation have a bearing on the consequences of disclosure that it is far more difficult to envision a sustainable rule that does not absolutize truth telling. However, where practitioners intervene in family relations they would seemingly have some obligation to minimize foreseeable adverse consequences.¹⁶

In all such instances, practitioners seem to be operating less from an individualistic model of autonomy than an implicitly relational one that appraises family interests collectively. Attempts to incorporate a relational perspective illumine two defects in the dominant individualistic structure. First, they illustrate specific inadequacies in a framework that operates from an abstract, noncontextual set of primary principles that may have significantly different implications as contexts vary. Second, these instances have very different implications for family harmony than is the case with dominant disorders. Open disclosure would be more likely to exacerbate tensions than relieve them. Neither of the family decision-making models discussed above seems adequate to protect the interests of the individual most immediately affected by the decision. Further protections are needed to insure equitable treatment to all family members affected by a medical intervention. Respect for autonomy would seem to require respect for both communal matrices and individual decision-making capacities.

Authority over testing their children

Thus there is good reason not to abandon a rule-based approach altogether. For the individual who is most vulnerable and has the most riding on the decision deserves the protection that an adequately formulated principle of autonomy can afford. Competing claims of other family members ought not to be allowed to trump hers. Her interests should not be reduced to a kind of balancing act between the interests of siblings. The protection of young children's future interests calls for an approach that gives less weight to the immediate concerns of parents and more to the children's futures, understood broadly to encompass not only physical well-being but also capacities for autonomous self-determination. Such an approach

16. Where testing indicates that the father who worried about his carrier status is not a carrier after all, he might be so relieved to learn the truth that the accompanying information about the child's biological paternity would seem insignificant by comparison. Even where the practitioner has reason to believe the social father would be distressed, the importance of disclosure may clearly override any adverse consequences. In situations where the study provides little new information about the social father except that the child is not biologically his, the more common practice is to disclose the results to the mother and let her decide whether to inform her husband. Many practitioners believe that at least she should be informed, since this information might have considerable impact on future childbearing decisions. Where the mother is the primary patient, this strategy maximizes her capacity to make future decisions autonomously. But if the couple were later to split up and the father continued to harbor guilt about an affected child, the same information might have an important bearing on his future decisions too.

would be responsive to the complaint of the son in "The Gift" whose father preempted the future that would have been open to him had he left his son's sexual identity and athletic gifts to chance instead of imposing his own preferences. Stronger moral protections are needed to safeguard the future well-being and choice-making capacities of children and others who are temporarily unable to speak for themselves. Here providers have to squarely confront the responsibility to consider the impact of their intervention on family relations.

Several national regulatory bodies and medical association have established policies aimed to limit parents' decision-making authority. Further protections are needed to insure equitable treatment for all family members affected by a medical intervention. Respecting everyone's autonomy requires attention to both their common relational matrix and individual decision-making. To safeguard the children's future autonomy and protect their confidentiality, they recommend that practitioners refuse to test children for genetic disorders unless there is a therapy available to treat them or a medical benefit to be derived from monitoring their condition. Some parents object, charging "paternalistic intervention" that infringes on their own autonomy. Though many parents are reluctant to discuss their own risk with their children, they are often so eager to learn their child's risk that many pressure practitioners to make exceptions to their policy against testing children.¹⁷ For the fact that adults often choose to decline testing for serious conditions once they fully understand the implications of a test indicates that the future decision-making powers of children are indeed compromised where parents preempt them. Moreover, children who do test positive are vulnerable to stigmatizing treatment both within and beyond the family—even before the onset of any symptoms. Only an exceedingly narrow view of personal autonomy could justify the disclosure of knowledge that can so adversely affect children's future capacities for self-determination. Second, even where a direct gene test is available to the individual seeking diagnosis, the results may have striking implications for the future of others, so much so that even those who test negative for the disorder may need to reconstruct their autobiographies and reconfigure their family relationships. Some, for instance, may feel a heightened sense of family responsibility, believing (falsely) that their negative result will affect the chances of other family members. Others may have trouble reconciling ambivalent feelings about family members with this new information. Thus any decision an individual makes about testing will reverberate throughout the biological family and affect their social families as well.

I turn now to genetic contexts which resemble the scenario in "The Gift" where the father intercedes to control his son's future options. I will consider several types of situations. First, a seriously ill minor child can best be treated if an existing HLA matched sibling contributes her bone marrow. A second pertains to a situation where no existing sibling has matching tissue. It utilizes preimplantation techniques (either PGD or PGS, Human Leucocyte Antigen) to conceive a child who will be a tissue

17. Wertz reports that 23% of HD clinics tested children under 12. See "Parents' responses to predictive genetic testing in their children" in *Journal of Medical Genetics* 1996; 33:313-318 and Wertz and Fletcher 2004. In Marteau and Richards 1996 see articles by Michie, Ball, and Tyler. Also Harper in Clarke 1994 and the policy statement "Ethical Issues with Genetic Testing in Pediatrics," American Academy of Pediatrics (*Pediatrics*, June 2001).

match for an existing child. Following birth her umbilical cord blood cells is collected and eventually transplanted to her sick sibling. Both types of situation are referred to popularly as a “savior sibling” issues. Then I turn to situations that are intended presumably for the “good” of a child whose embryo is selected. An embryo is chosen free of a specific genetic condition that would affect that child from infancy. Then I consider a situation where embryo selection aims at avoiding a condition that would not manifest itself until later in that person’s life. Finally, I return to the kind of situation portrayed in “The Gift,” selection of traits that would either enhance the offspring’s normal capabilities (such as athletic prowess) or carry out parental preferences for a child of a specific sex. In each instance I discuss autonomy-related issues and consider the advantages and limitations of both the standard individualistic analysis and a relational one.

A minor child risks dying from leukemia that can be treated only by a bone marrow transplant. Only her mentally handicapped sister is a good match. Since the parents have conflicting interests in the well-being of both children, a judicial opinion is sought. The court concludes that the physical risk involved in surgery to retrieve the marrow from the handicapped sister would be outweighed by the psychological benefits conferred on her¹⁸. For if the sister with leukemia dies, not only would her sibling be denied her companionship, but the grief-stricken mother could not continue to provide the retarded sister with the maternal attention she had grown accustomed to.

Similar cases have come before the courts in several countries.¹⁹ They commonly use this individualistic balancing strategy, weighing actual physical burdens against hypothetical psychological benefits to the donor. Almost always where the children have a social as well as biological relationship, the court rules in favor of the donation. So the healthy child is compelled to undergo a nontherapeutic surgical procedure for the sibling's benefit.

The degree of conjecture involved in this reasoning strains credibility. Two responses are paramount. Those who accept the terms of this individualistic discourse question the motives of the courts in not adhering more single-mindedly to a decision-making standard based on the donor's best interests. They wonder whether the calculus of burdens and benefits is skewed in a way that sacrifices the retarded sister's interests to her "normal" sibling's. Were she a competent, autonomous decision-maker herself, she would be able to deliberate with other family members, reflect on the value to her of relationship to them, and voluntarily make her own judgment. Those inclined toward a more relational discourse will focus on

18. Aneuploidy or PGS involves removing a single cell from an embryo to check for chromosomal errors that could affect normal development. It differs from PGD in which an embryo is tested for a single gene disorder. Some fertility experts recommend screening all embryos following IVF to caution until more is learned about the potential benefits and harms of the technique. For details see Bionews@progress.org.uk 10/24/05.

19. This case is drawn from British legal opinion, but US courts have employed similar reasoning in cases involving incompetents. The most celebrated is *Strunk v Strunk* (445 S.W. 2d 145 (Ky. 1969)). Dwyer and Vig (1995) discuss a number of others too. Their essay builds a case for a less individualistic decision-making standard and draws analogies between organ donation between siblings and more mundane situations where children are commonly expected to take responsibility for one another.

the tension between two moral discourses about family connection and wonder why courts are so reluctant to openly espouse a more relational model. Within a discourse that takes mutual responsibilities as an integral component of relationships among people whose identities are woven into a common history, the standard individualistic account leaves out too much. For the moral relevance of family connection is not reducible to individual interests. In actual families, children have responsibilities to one another long before they develop capacities to avow them voluntarily. Preparation for autonomous adulthood includes experience in caring for those one cares about and learning to recognize one's own needs through responding to theirs. Lacking such skills, adults are ill-fitted to build enduring relationships with others on a foundation of mutual reciprocity.

The individualistic discourse, however, does afford protection to the child asked to make the sacrifice that may be lost in a relational account unless it is attentive to power relations among family members. For were courts to shift their discursive frame and supplant the best interest standard with a relational model, they would still need to judge the scope of a child's responsibility for a sibling's well-being. Children need protection lest they be treated, Cinderella-like, as mere conveniences to advance others' ends. An adequately formulated relational model would incorporate such protection in any account of the moral responsibilities family members owe one another.²⁰

A somewhat different set of moral issues arises when a couple does not have a healthy child who is the right match to donate bone marrow to a sibling suffering from leukemia or potentially lethal anemia. Some afflictions can be successfully treated by a stem cell transplant from the umbilical cord blood of a compatible donor child. Where no compatible child exists some parents have decided to conceive another child. Before the development of PGD, the procedure utilized in "The Gift," they had to wait until the pregnancy was well advanced to screen the fetus for tissue compatibility. Some had abortions when prenatal testing showed the child would not be a suitable donor. With the development of PGD, it is now possible to substitute for the risk and trauma of late abortion a procedure prior to implantation. First carried out in 1990 PGD has since resulted in the birth of over 1000 children. Using IVF techniques or ICSI, (intracytoplasmic sperm injection) one or more cells are removed from a three to five day old embryo. They are then tested for a gene mutation or chromosomal abnormality that causes a particular genetic disorder. Unaffected embryos are transferred to the woman's womb to continue developing. Since all the cells that make up the embryo at this stage are "totipotent"—able to develop

20. Such relational tugs are common in many other medical decision-making contexts too. They may become intense where a family's blood is tested to determine compatibility for organ or tissue transplantation. Tests sometimes reveal sensitive information that practitioners feel obligated to protect. They then set aside principled injunctions to honor truth telling and selectively withholding information from a patient who needs bone marrow, a kidney, or a slice of liver. The patient is not told that a family member is a good match but refuses the surgery required to retrieve the tissue. Knowledge of the refusal, these practitioners claim, would have a disruptive effect on family relations at a time when they are already under stress. This practice is sometimes criticized as a kind of quasi-paternalism that elevates the interests of family members who refuse to contribute over the interests of the patient which should, in the judgment of these critics, be paramount. The reversal in priorities from the patient seeking knowledge to protection of information concerning other family members merits more thoughtful appraisal in light of the differences noted above between two different formulations of family interests.

into any body tissue—removing a single cell is believed to have no effect though this will not be known precisely until longer-term studies are undertaken (Bionews@progress.org.uk 06/20/07, BBC News Online, 8/18/04 <http://news.bbc.co.uk/1/hi/health>).

Interventions prior to pregnancy also reduce medical risks to the donor child since she need not later undergo surgery to retrieve her bone marrow. However, in one recent case, the British regulatory authority denied a couple permission to utilize this technique. They argued that the donor child would receive no benefit from the intervention. In another case that was similar in all but one respect, the sick child was suffering from a genetic disease, they granted permission to use PGD. They reasoned that the donor child would benefit since she would be born free of the disease that afflicted her sibling. While the case was under appeal the second couple traveled to the US where any couple with the financial means can opt for either PGD or fetal diagnosis.²¹

The British decision has been much criticized within Britain for overstepping the authority of the regulatory body. Though this scenario was not envisaged at the time the British regulatory legislation was initially passed, concerns addressed by the legislation are extendable to the present circumstances, specifically the welfare of the child and the well-being of the family. Subsequently the Human Genetics Commission (HGC) expressed concern over the extent to which children are used to benefit others (2006). They reasoned that once it is accepted in principle that children can be created to save the lives of siblings, more extensive or repeated tissue donations may come to be regarded as equally permissible. They also feared that parents who have an affected child might not fully understand the range of options available to them. They urged that the rights of parents be balanced against the well-being of the child and the wider interests of society.

Though the use of PGD raises unique issues, in some respects the savior sibling concerns are reminiscent of a situation common in past generations when the incidence of infant mortality was much higher than today. Following the death of a much loved child, bereaved parents often conceived a “replacement child” to console them for the loss. This child was often seen as the reincarnation of the first child and the hopes and dreams the first child represented. Not uncommonly this child was the subject of unfavorable comparisons with the deceased older sibling.²² Today’s savior siblings are at risk of similar treatment, especially so when the therapy which motivated the conception of the younger child doesn’t achieve the intended purpose and the older sibling dies. Then parallels between “replacement child” experiences and the current controversy are most striking. Both situations prioritize parental wishes and influence the child’s future options. However, the intervention of medical practitioners further complicates decision-making options. Unlike past situations when such conceptions happened

21. For extended discussion of the HFEA see Chapter 2 above. For details about these cases see the editorial, “A Tale of Two Youngsters,” *New Scientist*, 08/10/02. For further analysis see David Wasserman, “Having One Child to Save Another,” *Philosophy and Public Affairs Quarterly* 23:1-2, 2003, 21-27.

22. This parallel occurred to me while reading Matthew Von Unwerth’s account of Vincent Van Gogh’s plight as a “replacement child” in his book, *Freud’s Requiem* (New York: Penguin, 2005). Note, particularly, pp. 153-154.

spontaneously, they are now assisted by third parties. The availability of PGD adds an additional layer of complexity.

For unlike predictive testing of children after birth which affords no therapeutic benefit to the child, PGD followed by embryo selection determines the genetic identity of the future child and shapes the mother's pregnancy experience. Though the father was primary decision-maker in "The Gift," it was the mother's body that had to be invaded to facilitate laboratory inspection and selection of embryos. Presented in "The Gift" as a futuristic technique, commercial diagnostic laboratories are now offering PGD for a fast growing array of single gene disorders.²³ After taking their own life circumstances into account, adequately informed women are likely to make very different judgments about whether the risk, disruption, and anxiety are worth it to them.

Other genetic innovations force further morally repugnant choices on women. For the single-gene disorders I have mentioned, few women would choose to undergo PGD unless the condition is already present in their family. PGD for adult onset disorders such as HD or genetically linked breast cancers raise still other moral quandaries. Daughters in affected families who anticipate pregnancy along with women already pregnant are likely to be extremely anxious about diagnosis. Ultimately, some may decide to gamble on pregnancy in the hope that a cure will be found in future years before symptoms develop. Others may be too overwhelmed by the prospect of transmitting such devastating diseases to accept that gamble.

Many genetic anomalies are not discovered until after birth. Since women are the primary caregivers of infants (as well as of disabled people of all ages), they are often the first to notice that their infant is not developing properly and they must seek out medical advice, battling their way through a health care system which has historically depreciated a mother's observations. Coupled with the fact that most general practitioners have little or no training in medical genetics, a concerned mother may need exceptional tenacity and determination to defy disparaging misinformation ("your baby is just lazy or placid" or "you're a neurotic mother") and reach a consultant qualified to offer an informed diagnosis and provide the information and support she needs to deal effectively with her child's problems.²⁴

Such complications place multiple strains on family relationships. Family members who may have drawn apart from one another may discover that their fates are intertwined in ways they can no longer evade. Sometimes family communication breaks down. Individuals within a specific family may use very different strategies to cope with their sense of powerlessness in the face of a wholly random

23. These include Tay-Sachs disease, muscular dystrophy, hemophilia, fragile X, Down syndrome, HD, and achondroplasia.

24. Misinformation is very common with such conditions as spinal muscular atrophy. For a fuller account, see Harper 1996.

event. Some deny the condition; others undertake a compulsive search for knowledge (Wexler, 1992).²⁵ Following definitive testing, the more fortunate members may experience "survivor guilt." The unfortunate ones may blame parents and hold them accountable for their disability. If the disorder is X-linked, a mother may bear the brunt of resentment since it has almost certainly been transmitted through her. Parents undertaking prenatal diagnosis who already have a child with a genetic anomaly sometimes feel deeply ambivalent about aborting an affected fetus, fearing that their living child may later interpret the abortion as a personal rejection. Brothers, sisters, and parents will all be drawn into a tangled web of interconnection laden with tension and conflict. The strain will also extend to others who are in committed relationships to those at risk, thus threatening relationships beyond the biological family too.²⁶

Particularly conspicuous in affected families is the extent to which test results may disrupt family expectations--which are bound to influence how family members shape their identities and negotiate family positioning. Beliefs about roles, relationships, and individual characteristics often play a significant part in constituting individuals' identity and their place within the family. Family therapists speak of "family scripts," preexisting systems of beliefs about family relations within which a new member is integrated. As one's self-conception develops within a constellation of relationships, questions emerge about how one wants to live one's life against the background of this personal history.²⁷ Even the name given infants at birth (the Smith family's choice to name their son "Adam", for instance) may both reflect and shape expectations of their child's place within the family and future life choices. My own younger sister was named for our mother's much loved brother who died in his teens. She felt doubly burdened: marked as the wrong gender and assigned a role as our mother's confidante that no young child could possibly fulfill. As she gained autonomous self-direction, she turned to her own peers for the support she felt lacking at home. In families with inherited genetic disease, family scripts may be far more difficult to overcome. Families sometimes cope with uncertainties about which member might inherit a familial condition by "preselecting" one of their own who they believe is affected. Then they interpret the behavior of that individual in ways that fulfill their prophecy. If this person subsequently

25. Among themselves, genetic counselors refer to these people as monitors and blunters. Monitors can't live with uncertainty and want to know everything. Blunters don't welcome any information. They can't be engaged in any substantive discussion at all.

26. For a fuller account of such situations see the fascinating chronicles of personal experience with genetic disease included in Marteau and Richards 1996.

27. Diana Meyers calls this "programmatic autonomy" and she distinguishes it from "episodic autonomy" which focuses on particular situations. Personal autonomy in her account is a function of these two (1989). My own account of autonomy resembles some features of hers but puts less emphasis on the inner psychological states of the individual subject and more on outer relations that enter into inner representations. Shifting the locus of consideration in this way brings out interconnections between individual efforts to shape an autonomous identity, social structure, and personal history. This shift in emphasis brings patterns of power and authority into clearer focus. For further discussion of their distinction see Addelson, 1991, Ch. 11.

tests negative for the condition, she may be even more severely ostracized by the family than if the result had been positive! (Richards 1996).

Family Tensions Generated by External Conditions

Material conditions originating outside the family may exacerbate tensions within it too. The vagaries of insurance and employment practices will intensify psychological stresses. Unless medical confidentiality can be assured, even a family member who has not been tested herself might lose her job or insurance if the test results of others in the family leak out. In one case, a woman in her fifties requested a direct gene test for HD. Her son and daughter-in-law protested, claiming they should have a voice in the decision to test the woman too. According to standard accounts of autonomy, their interference would surely be unwelcome. But as it turned out, the son had good reason to be fearful of the effects of the test. His employer had been seeking just this kind of information. If his mother tested positive, his own job would be threatened.²⁸

The threat of job termination is closely interrelated with the risk of disclosure of genetic information to insurance companies. For where employees have health insurance coverage through their employer, premium costs to the entire group may increase substantially when even a single employee is overtaken by an extended illness. In the kind of unregulated environment that prevails in the US consumers are afforded no protections against the disclosure of genetic test results to any interested parties. Buchanan points out that failure to protect people from widespread genetic discrimination in employment and insurance threatens to discredit the chief public justification for using public monies to finance the Human Genome Project (2000, 262). The current situation is exacerbated by the lack of universal health care coverage, the spiraling cost of health insurance provided both through employers and paid directly by consumers, and the rapidly growing proliferation of genetic tests available to those undergoing IVF despite evidence that they are often clinically unjustified.²⁹

While the US Congress deliberates about passing legislation prohibiting discrimination against at-risk individuals by insurance companies, commercial testing laboratories have stepped into the breach. They are marketing direct access testing (DAT) for genetic conditions which bypass a visit to the doctor

28. Personal communication. Unless otherwise indicated, all cases are direct reports of actual cases provided to me by staff of genetics clinics. This case is by no means unique. For instance, fear of the loss of insurance deters many women with a family history of breast cancer from testing for the presence of BRCA1 and BRCA2 genes despite the advantages of early detection.

29. Katy Sinclair reports that according to Lord Robert Winston (one of the leading fertility experts in the UK) genetic tests offered to those undergoing IVF are often misrepresented (Bionews 6/6/07). I would assume that this observation holds for the US as well.

or counselor. They applaud DAT as a means to protect patient privacy by keeping information out of patient medical records. Web sites are advertising at-home ““nutrigenetic”” DNA test kits. Using a DNA sample from the consumer--a swab from inside the cheek or a spot of blood--the kits claim to analyze a limited number of genes, then provide diet and lifestyle tips tailored to the consumer’s genetically determined risks. In a 2006 article, Lucy Modra defends the view that this corporate-consumer relationship is not inferior to the health care system in promoting the autonomy of patients who seek genetic testing. Perhaps under ideal conditions both options might be comparable. But under prevailing conditions, the DAT alternative is far more likely to compromise patient autonomy than the health care system. It’s been found that the reports provided by DAT companies are far from accurate. The health care system incorporates somewhat greater assurances that medical findings are accurate and provide comprehensive information. Moreover, consumers who go the DAT route would still be dependent on the medical system when their reports are positive for genetic risk, and further testing is called for. Moreover a recent US government report on kits from four such Web sites found that they are misleading at best, and cleverly disguised scams at worst.

The Government Accountability Office bought fourteen genetic tests from four online vendors.³⁰ It then used samples of DNA from two individuals to create fourteen fictitious consumers with a range of ages, weights, heights, and lifestyles and sent the samples for analysis. Kits from one site predicted an increased risk of the same four diseases for three of the fictitious people whose DNA came from the two subjects. Advice based on DNA from the same ““person”” varied with the lifestyle profile provided by the investigators. (Smokers were advised to quit; healthy eaters, to keep up the good work). Most disturbing, two sites recommended ““personalized”” dietary supplements which were supposed to repair damaged DNA (presently, no pill can do this). The supplements suggested by one site turned out to be garden-variety over-the-counter multivitamins and antioxidants. At the time the report was released, only a dozen of the almost 1,000 genetic tests available, whether meant for use at home or under a doctor’s care, had been reviewed and approved by the US Food and Drug Administration. Hopefully, the report will spur increased government oversight of this marketing ploy and more efficacious privacy protections.

To sum up, family conflicts coupled with the increasing availability of commercial genetic testing forcefully illustrate that however diligently people may struggle to forge a discrete identity in isolation from familial and societal influences, identity is never wholly within an individual's power. For individual identities are partly defined by their relations with those with whom their lives are intertwined and partly by material and social conditions over which individuals have little direct control. The conditions under which one is nurtured and reared and wins the support and affirmation of others intersects their fortune in the natural and social lotteries. Families tend to reflect, and often exacerbate, prevailing social injustices. Social conditions may be rigid and immutable or flexible and malleable depending upon family constellations and the resources a society invests in compensating for the ill-fortune of the less well off.

Effects of Genetic Information on One's Self-Conception

30. This report is available at www.gao.gov

Huntington disease (HD) provides a particularly striking example of a genetic condition that intrudes itself into the lives of individuals and families in critical ways and imposes complex demands on those who counsel affected families. When families are reluctant to inform other kin who may be at risk, practitioners may be tempted to intervene to pass on information. A curious spin on this theme is illustrated by the case of a 29 year old woman who comes to the genetics clinic for counseling because her mother had told her that she (the mother) has tested positive for HD. The mother, the counselor learns, has a long psychiatric history involving drug and alcohol abuse. The daughter is an only child whose father left home early in her life. The mother and step-father both abused her. The counselor gains access to the mother's records and finds out that she actually tested negative for HD. She contacts the mother who refuses permission to tell the daughter that she does not have the disease.

The counselor has multiple moral responsibilities here, but it is by no means clear where her primary obligations fall. Within a bioethics framework based on general moral principles, the conflict would be framed in terms of two guiding principles: respect for the daughter's right to make autonomous decisions and the mother's right to confidentiality.³¹ Geneticists and trained counselors who regard confidentiality as sacrosanct would disregard obligations to the daughter rather than breach confidential information. The tested individual, they often argue, has a stronger claim to the information than other family members, so she ought not be compelled to disclose the information (Clarke 1994, 14). The counselor who overrides the mother's refusal is vulnerable to charges of "clinical imperialism" (Richards 1996:266). Philosophers and legal theorists are more likely to grasp the dilemma by the other horn and stress the importance of accurate information for the daughter's future plans. They might argue that the geneticist has the responsibility to share her knowledge of the deception so the daughter can free herself from the influence of her over-controlling mother. For those who follow this line of reasoning, the daughter's claim to information so vital to autonomous pursuit of her own goals would trump the mother's claim to control over that information.

Some philosophers would be likely to use such a situation to show how autonomy might push toward disconnection from relational ties. Marilyn Friedman points to an underlying tension between thinking that autonomy may sometimes give way to relational values and thinking of autonomy as in itself relational. Relational accounts of autonomy, she cautions, may obscure harmful influences of social relationships, thereby obstructing the actual exercise of autonomy (1997, 55-56). Some relationships might be so destructive of autonomy, she believes, that autonomy can only be maintained by severing relational ties. The mother who withholds from her daughter genetic information relevant to the daughter's decision-making illustrates one dimension of relationships that become an obstacle to the realization of autonomy. It is not difficult to imagine other contexts that illustrate this phenomenon. Many

31. It has become fairly common to speak of bioethicists who ground their theoretical accounts in a set of primary principles (such as truth telling, autonomy, justice, and beneficence) as "principlists." Beauchamp and Childress are often cited among the chief exponents of principlism (2001). For discussion of principlism and its critics see, for instance, *Kennedy Institute of Ethics Journal* 5,3, 1995. In a pertinent article in *Bioethics* Erica Lucast argues that these principles provide a good foundation for medical practice but they are not fine-grained enough to guide the counselor in her decision about disclosure (2007). I share this assessment.

academics have left their native country to pursue better professional opportunities elsewhere. In some instances, they have angered parents who remained in the home country who could not understand their decision, so their autonomous choice to leave had a negative impact on close relationships.³²

How a Relational Conception Illumines Family Conflict

Clearly, a more nuanced account of relational autonomy is needed that recognizes both autonomy-fostering and autonomy-inhibiting aspects of social relationships. In fact, any account of autonomy that preserves even minimally Kantian features will recognize that what we *want* for ourselves may run counter to our autonomy if it can only be attained by dodging responsibilities toward others who depend on us. Respect for their interests and their autonomy may sometimes bump up against our own autonomy-advancing plans and goals.³³ Moreover, autonomous pursuit of one's good is bound to intersect others' pursuit of their good. For following one's own sense of the good life inevitably binds us to schemes of social cooperation over which we may have little direct influence or control. Some of these may be only instrumentally relevant to our own pursuits but others will inevitably be substantively bound to ongoing projects, so that one's desires and preferences will be intrinsically interrelated with those of others. Only minimal reflection on relational dimensions of autonomy is needed to show that personal autonomy can trump other morally significant values only in certain very limited contexts.

On my account, then, autonomy is relational in at least two senses: pursuit of autonomy is not solely an individual enterprise but involves a dynamic balance among interdependent people tied to overlapping projects; and the self-determining self is continually in the process of refurbishment within a context of relationships that is continually in flux. A relational understanding of autonomy, then, is not incompatible with subordinating one's personal projects to the needs or preferences of others so long as no one's autonomy is trampled upon. Respect for each's autonomy, however, requires long-term reciprocity and equitable balancing of power relations. These conditions put constraints on an individual's freedom to "opt out" of a relationship, but they might justify opting out where mutual respect cannot be sustained even minimally or when the pursuit of an individual's central life goals can only be furthered by severing the relationship. Whether opting out is a live alternative will depend, of course, on the resources available to the person who wishes to terminate the relationship.

32. I am grateful to Arleen Salles for pointing this connection out to me as well as for many other pertinent suggestions.

33. In her essay "Abortion and Embodiment" (1992), Catriona Mackenzie provides a carefully nuanced analysis of responsibilities of the pregnant woman toward her fetus which aims to show how abortion is most fundamentally about women's self-determination. The fetus's moral status, she argues, depends not only on its intrinsic properties but on relational properties it has with others, particularly the woman carrying it. These relational properties are continually in a process of change as the fetus's intrinsic properties develop and the pregnant woman's bodily subjectivity alters. Her analysis of relationships between self-determination, embodiment, and responsibility has far-reaching implications for other contexts too, some of which I allude to briefly here.

The tension that Friedman alludes to surfaces here in the relationship between the daughter who is seeking genetic information pertinent to her own future plans and the mother who withholds relevant information. By way of illustrating the conception of relational autonomy I am advancing, I will focus on several features of their relationship and responsibilities of the counselor by virtue of her professional relationship to both mother and daughter.

Insofar as she is responsible for respecting the autonomy of both parties, she must decide how to use information the mother has withheld that is pertinent to the daughter's decision-making. If the counselor is not, herself, to contribute to severing their ties, she will explore possible routes between the horns. Mapping such routes, though, calls for a framework more compatible with the nature of genetic knowledge than the language of competing claims, a framework that recognizes the interlocking relevance of genetic knowledge for the entire biological family. In this one significant respect, at least, mother and daughter are not free to sever their relationship. Because the statistical risk of a particular family member can be inferred from tests performed on biological kin, professional confidentiality cannot insure the protections appropriate to many other types of medical information. The reasons usually advanced for protecting individual privacy have less weight here since the information is not unique to any member of the biological family. Hence the counselor has no morally compelling reason to conceal such information from other family members who might be similarly affected.³⁴ Of course, knowledge should not be forced on anyone unwillingly either, but others who share the blood line and actively seek the information have at least a *prima facie* claim to it. Nonetheless, there might be excellent reasons for protecting the confidentiality of the family collectively (potential discrimination, etc.).³⁵

Hence a conceptual framework that puts a premium on personal privacy is misplaced and misleading in these contexts. The awareness that genetic information is shared among kin is implicit in both the mother's deception and the daughter's quest for further information about her own risk. For both know that their fates are interlinked. If the mother is affected the daughter has a fifty percent risk of acquiring the disease too. If the mother does not have the gene, the daughter's risk is reduced to nil (assuming the father is unaffected). A framework of moral responsibilities that slights the daughter's request for knowledge about her own susceptibility not only obscures the nature of the information at issue but also impedes her capacity to shape her own future autonomously. Such a framework also overlooks harms that might come about from use of this information to manipulate power positions within families and exacerbate injustices to more vulnerable members.

Standard accounts of autonomy may distort the actual dynamics of family relationships in a further respect too. For a language that prioritizes competing claims presupposes that people are normally

34. For stirring my thinking about this feature of genetic information, I am indebted to Paula Boddington's 1994 essay.

35. In this respect, the situation is analogous to those involving sexual partners of people tested for HIV/AIDS. If the tested individual is negative and gave the partner false information, the health care provider is confronted by a similar quandary: whether to respect the confidentiality of each individually or to treat both conjointly.

at odds with one another. On some occasions, they surely are. A shift from the individualistic discursive frame to a relational one recasts their conflict and reframes it within the context of their complex longstanding relationship. So even where the influence of one family member hinders pursuit of the other's autonomy, steps might be directed toward reconstituting their tie on a more equal footing rather than severing the relationship entirely. Turning away from an individualistic norm to the relational situation that frames the immediate conflict opens the way to further strategies for resolving tensions, reducing injustices, and reconfiguring self-understandings. Mother and daughter could possibly be reconciled on a new level informed by the backward and forward looking meanings this new knowledge has for their conception of one another. And if reconciliation is not possible on terms acceptable to both, the counselor's empathetic support can nonetheless contribute to integration of this new knowledge into their individual self-understandings. Susan Brison's evocative account of her own experience as a trauma survivor reveals the deeply social nature of the self and the limits of an individual's capacity to control her own self-definition (2001). To reconstitute a unified self out of the disintegration that followed violent assault, she needed empathetic and responsive listeners. Disclosure of vulnerability to genetic disease can precipitate a similar crisis in the face of a threat that one can neither fight nor flee, damaging one's sense of wholeness, one's reliance on the integrity of mind and body, and connections between self and others that are essential to combating defenselessness in the face of life threatening forces and forebodings about a foreshortened future.

Brison stresses the importance of connections to family and other intimates at these times, not only for their nurturing support but also as a repository for collective memories and rituals that sustain the sense of a unitary self able to persist through crises. In families plagued by disabling genetic disorders, narratives about those who coped with the threat of disease can serve many of the functions of support groups. Professional counselors encourage affected families to seek out groups that can offer survival strategies, but often fail to recognize the family's centrality in sustaining the sense of bodily integrity of the affected member.

Too often family is perceived less in terms of their shared history and intertwined identities than as a group of disparate individuals with a common pool of material resources and reciprocal obligations to provide care in times of need. John Hardwig argues that where families will be affected by a decision, fairness requires that family have a role in reaching it. He believes that occasionally the interests of other members might outweigh the patient's own (1990). Hilde and James Lindemann Nelson disagree (1995). They point out that Hardwig's position not only runs counter to the dominant priority given individual autonomy, but it also ignores the fact that the patient has a greater stake in the decision than anyone else. Certainly, family should have an input in deliberation, but family motives and concerns are better aired in the open where the intricate network of their relationships can be protected from break-down. Practitioners who cast people in conflicting relationship increase the likelihood that they will see one another as adversaries. Jeffrey Blustein concurs. He argues that the locus of decision-making authority should remain with the patient. Moreover, echoing Brison's point, he emphasizes that by virtue of their closeness to the patient and intimate knowledge of her, family members may be uniquely well qualified to shore up the patient's vulnerable autonomy and assist her in making an autonomous decision (1993).

This disagreement runs deeper than the decision-making scenario around which it is focused. Hardwig's formulation of the issue takes family conflict as static, a function of each individual's separate

material interests which are unaffected by the physician's intervention. The Blustein and Nelson approaches hold providers responsible for fostering family communication and seeking reorientation of the perspectives of interested parties. They understand the family as a dynamic interlocking structure that is not reducible to its separate parts. Only such a perspective is compatible with the sense of a shared past, of overlapping memories and rituals that Brison sees as so vital to the restoration of the psychic integrity which is indispensable to the capacity for personal autonomy. The shared nature of genetic information provides a further ground for reorienting the functions of genetic counselors to reflect a deeper understanding of the complexity of family relations so that they can devise more effective strategies to enhance the autonomy competencies of each of their clients.

How access to Knowledge Bearing on Future Plans and Conceptions of Relations Affect Autonomy

In the last section I alluded briefly to injustices to individual family members that a relational account of autonomy may too easily overlook. Here I return to this theme, focusing on injustices borne predominantly by women by virtue of their reproductive capacities and social positioning within families. My emphasis is on the importance of taking responsibility for medical intervention in the deliberations and decisions of both the particular family member under treatment and kin who share her genetic characteristics and participate in a common relational network. Providers, I will argue, need to be attentive to both particular circumstances and rule-based principles to guard against unjust treatment of family members who are expected to bear a disproportionate share of family responsibility. For family biases are further compounded where there is genetic disability. Care-giving and support functions are likely to fall predominantly to women and other family members are likely to see themselves as potential victims of the same biological incapacity (Williams 1994). First I mention major respects in which women's lives are likely to be more disturbed by new genetic knowledge than men's. Then I turn to the responsibilities this vulnerability imposes on providers who advise women and their families of their options, emphasizing the power of genetic knowledge to thwart or advance autonomy depending on how it is embedded in the clinical relationship.

Genetic information enters into family relations and impacts on family life along gender-specific paths. It is primarily women who are the central focus of the family-based problems that genetic diseases create (Harper 1996, 54). Both by virtue of reproductive capacity and social positioning, the role of family caregivers has traditionally fallen to women. Clinical arrangements tend to reinforce this delegation of family responsibilities. How burdensome such duties will be for any particular women, of course, will depend on her material circumstances and support network. But few women are so privileged that they can afford the degree of individual self-determination and independence from family ties that privileged men often take for granted. Women's lives are typically more immersed in kinship relations and more preoccupied with family, especially where they do not have the material resources to hire help for child and elder care. Many must depend on shared family arrangements to juggle their double day. Whether by choice or default, women bear more of the responsibility for monitoring health issues in families than men. They are the "kin-keepers" who do the family's genetic housekeeping. They tend to know more about the obstetrical history of the man's family than he--how many pregnancies his mother had, how many ended in miscarriage, etc. Since only about one in four women is accompanied to a

counseling session by a spouse or partner, prudent women may have no choice but to arm themselves with all the information they can muster.

As long as material inequities persist at the societal level, traditional expectations of women as primary caregivers will continue. A husband's or father's economic contribution to the family tends to reflect gender-based market disparities and usually represents a greater proportion of the family's cash resources than the wife or daughter's monetary contribution. Women are also more likely to be manipulated into self-sacrificing patterns of relationship where they subordinate their own well-being to care for others. Women are also more susceptible to pressures to follow the "expert advice" offered by health care professionals.

By virtue of reproductive capacity too, genetic knowledge is likely to influence women's lives far more pervasively than men's. First, only women undergo prenatal testing which is increasingly becoming a part of the customary prenatal care package. Not only women over thirty-five, but younger women too are increasingly being urged to submit to preliminary genetic screening procedures and follow-up diagnosis, not only where there is prior knowledge of genetic disorders in their family medical histories, but in other instances too. Prenatal diagnosis is already available for hundreds of conditions.³⁶ As DNA technology advances, laboratory procedures are automated, and a skin prick replaces more intrusive procedures, far more screening tests are likely to be included in routine prenatal care, further complicating prenatal decision-making.

Second, women endure more of the psychological stress generated by testing than other family members. A woman whose fetus tests positive for a genetic abnormality must make a difficult decision about terminating a wanted pregnancy, often on the basis of incomplete information. For their partners, prenatal diagnosis is likely to be a less immediate worry that can more readily be postponed or denied.³⁷ Infertility patients have an additional basis for anxiety since they already have a huge investment in the pregnancy both economically and emotionally. They also tend to be older, so fall into the "high risk" category which warrants more careful scrutiny. Genetic therapies might eventually provide an alternative to abortion following diagnosis of fetal anomaly. But these interventions will also be accomplished through the bodies of women. They carry their own risks which the pregnant woman will need to weigh in the light of her own values and priorities.

36 . . . cause serious mental incapacity--cystic fibrosis and hemophilia, for instance. For more detail see Andrews et al 1994, particularly p. 75, Andrews 2001, Flinter 2001. For feminist commentaries on treatment of these conditions see particularly Rapp 2000 and Rothschild 2005.

37. Gwen Anderson's 1990 study of a group of couples she followed through the pregnancy experience illustrates this phenomenon. The women in her study worried considerably more than their husbands about what they would do following prenatal diagnosis if the results were positive. In one case the worry was borne out and the worrier coped with the news far more effectively than her spouse. These range from profound mental retardation and early death, in the instance of some trisomies and Tay-Sachs, to disorders that affect daily living and shorten life span but do not non-worrying husband.

Compounding the disproportionate burdens imposed on women by virtue of their reproductive capacities are many gender-specific structural arrangements only remotely related to biological difference. After the birth of a genetically impaired child, women continue to bear a disproportionate burden. Recent medical advances that have extended the lives of people with disabilities together with cuts in public funding for social welfare programs necessitate even more protracted involvement of parents in the care of affected children. In many instances this will extend throughout the child's natural lifespan and may fall to siblings after the parents' deaths. In both extended and nuclear families, caregivers are increasingly dependent on public support which is seldom adequate to ease their burdens. The increased incidence of divorce under such stressful circumstances exacerbates the needs of the custodial parent, usually the mother. She is left with fewer resources and an even greater burden of responsibility. As governments privatize more caring functions and shift them to families, such women sink even deeper into poverty. Women who are rearing children alone and are themselves at risk of developing adult onset disorders bear an even weightier burden. Once symptoms manifest themselves even women in seemingly stable relationships may find themselves abandoned by non-vulnerable spouses and partners.³⁸

Poor women are particularly likely to confront a bewildering array of health care policies and practices compounding other problems of poverty. Women of color and other underserved populations are doubly disadvantaged (Marfatia 1990, Roberts 1997). The Black community in the US is still smarting over the sickle cell screening disaster of the 1970s and pressures on Black women to use birth control implants in the '90s. So they are less likely to find their way to a professional trained genetic counselor. For those who do, cultural differences may interfere with the communication and education process more extensively than for middle-class white women. Gaps between counselors' and clients' ways of knowing inevitably obstruct communication. If differences are profound, barriers to a decision responsive to the client's life circumstances and personal goals may be insurmountable. Since motherhood and family life are often more highly valued in working class and minority communities than among the middle classes, abortion is less likely to be viewed as a satisfactory solution to a troubled pregnancy. Women in these situations have an acute need for counseling that is responsive to the distinctive background conditions that shape their experiences, so they can map out alternative options that are compatible with the values they count most highly. To act on these options they need appropriate social support services too.

Medical practitioners who counsel patients play a pivotal role, imparting knowledge, offering advice, and preparing the ground for the reception of test results. Disparities between lay knowledge about inheritance and scientific accounts complicate their interchange. Lay accounts are often tied to cultural and psychological factors that resist scientific explanation. Words like "uncertainty" and "risk" tend to have different meanings for geneticists and lay people. For the professional, risk may mean the *probability* of a negative outcome; for the patient, it is more likely to connote the *severity* of the outcome (Richards 1996, Shiloh 1996).

38. Women are far less likely to abandon male partners.

Different kinds of problems arise where counseling is done by general practitioners or obstetricians, on the one hand, or by geneticists or genetic counselors, on the other. Studies have shown how important the profession of the counselor is to the patient's decision about terminating a pregnancy. Some are more directive in their approaches than others.³⁹ Obstetricians are most likely to offer advice about pregnancy termination rather than present options for the patient's determination.⁴⁰ Geneticists and genetic counselors are schooled in an ethos of nondirectiveness which pulls in the opposite direction. The counselor is expected to provide the facts that the client needs in order to make an autonomous, informed, and rational decision. These facts are to be balanced and given in a nondirective, value-free manner that respects the others' "beliefs, cultural tradition, inclination, circumstances, and feelings."⁴¹ Devised to protect patients from eugenic bias or other paternalistic interferences, the ideology of nondirectiveness is in actuality unworkable because it fails to recognize that the context that frames counseling already presupposes the importance of detecting genetic anomalies and interceding (Clarke 1991, Lippman 1991). This ideology also disregards other moral dimensions of the relationship. First, a nonselective barrage of information may overwhelm a patient and deny her the opportunity to relinquish control to trusted others. Second, because this approach promises a degree of neutrality that cannot possibly be achieved, patients may be inadvertently deceived and guided surreptitiously toward a course of action that defeats the primary intention of counseling: enhancement of autonomous decision-making. Third, judgements about which conditions merit discussion with clients are often value-laden (Caplan 1993, Brunger and Lippman 1995). Unless counselors take responsibility for the selectivity they inevitably exercise, they will inadvertently impose their own values, thereby jeopardizing effective patient reflection and deliberation. The tendency to impose values on the client will increase as the number of detectable conditions outpaces the supply of qualified counselors. Fourth, insofar as counseling is committed to a traditional scientific model that bifurcates facts and values, emotional dimensions of the client-counselor relationship will be suppressed, isolating the client from the kinds of empathetic support needed to restore a fractured identity or preserve a sense of wholeness in the face of trauma and family conflict. In sum, the illusion that counseling is value-free conceals important moral dimensions of the interaction that, if recognized and addressed directly, would clarify everyone's respective goals and empower the client to reorder her own moral priorities and assign them sufficient weight to counterbalance the competing interests of other family members.

39. See Clarke, 1994, 18. He attributes this information to M. Holmes-Seidle et al: "Parental decisions regarding termination of pregnancy following prenatal determination of sex chromosome abnormality," *Prenatal Diagnosis* 7: 239-244, 1987 and A. Robinson et al: "Decisions following the intrauterine diagnosis of sex chromosome aneuploidy," *American Journal of Medical Genetics* 34: 552-554, 1989. Marteau 1994 confirms this observation and Green 1996 cites additional sources supporting it.

40. A survey that sampled obstetricians in England and Wales showed that over a third would not refer a woman for genetic testing unless she agreed in advance to terminate an affected pregnancy (Green and Statham, 1996:150-151).

41. Quoted from the National Society of Genetic Counselors Code, 2.2, 1991. Cited in Brunger and Lippman 1995.

A new conception of genetic counseling is needed that replaces the nondirective paradigm with a non-hierarchically structured model that fosters a collaborative relationship which aims to enhance the client's capacities to exercise agency within her own relational context.⁴² The counselor might think of her role as analogous to a person from a distant culture who understands her own historic situation, appreciates how others might perceive her in the light of their cultural norms and values, and recognizes the complexities of others' life circumstances. In light of these considerations she might seek to free the client to make her own determination in a way that is responsive to her own needs and values without isolating her from the family and community.⁴³ The client might then make a decision about the centrality of family relations to her future goals. Ideally, the counselor would not see her role as terminating with the decision to abort or continue a pregnancy but strive to create a basis for a sustained relationship with the client and her family that extends beyond the immediate crisis. Such revisioning would advance genetic counseling beyond the prevailing nondirective model toward a more holistic understanding of family dynamics embedded in a relational understanding of autonomy.

Eugenic Considerations

Now that I have considered the social and institutional context within which genetic alternatives are framed and concerns about potential societal discrimination among populations judged to be "at risk" for genetic disorders, I turn back to two central issues raised by "The Gift," the implications of projects to eliminate all embryos that carry genetic anomalies and the laboratory modification of embryos to enable parents to select traits of their own choosing.⁴⁴

Unlike the diminished concern about sex selection, there continues to be emphasis on preventing the birth of children with disabilities. Two policy developments are particularly noteworthy. In 2007 the American College of Obstetricians and Gynecologists (ACOG) recommended that testing be offered to all

42. In her essay "Interviewing women: A contradiction in terms," Ann Oakley (1993) attempts to formulate such a model within the context of the relationship between a research interviewer and her interviewee. With appropriate modifications the model she devises could be transported to the counselor/client relationship. She develops this model more fully in her *Social Support and Motherhood* 1995.

43. Maria Lugones's evocative essay "Playfulness and world-traveling" (1987) suggests a strategy for suspending the norms of one's own world and acquiring the sense of multidimensional reality needed to understand oneself through another's eyes.

44. LP: This section is clearly incomplete. However, there is an extensive discussion of such issues in what I believe is an earlier version of this chapter. It covers sex selection and more purely eugenic issues described in this introductory paragraph. AD imported discussion of sex selection into what is now chapter 6. What follows here is imported from that earlier draft here by me; I have done my best to reconstruct this sometimes incomplete section.

pregnant women regardless of age.⁴⁵ Though newer techniques now make it possible to analyze fetal DNA to identify at least twice as many harmful variations as with previous methods, the clinical impact of such test reports is still uncertain. If prospective parents are not fully informed they might decide to terminate a pregnancy on the basis of misleading information. To forestall this scenario the U.S. Congress passed the Prenatally and Postnatally Diagnosed Awareness Act in 2008.⁴⁶ The law is designed to correct and supplement a pregnant woman's understanding of the clinical implications of genetic testing and her knowledge about what life is like for children with disabilities. Rebecca Dresser in her comments about passage of the Act notes that such information is an important step toward treating patient choices about pregnancy in the same manner as other health care choices. However, it is not enough. Physicians and counselors must take care to frame and present information in a manner that does not subtly influence the recipient.⁴⁷

Much of the controversy about new uses of PGD was not foreseen. I have already discussed its use to help couples conceive tissue-matched babies to treat sick siblings. Like the scenario in "The Gift," PGD has also made it practicable to use sex selection for non-medical reasons, to test for diseases (such as HD and BRCA mutations) that do not appear until adulthood, and predispositions to multifactorial conditions that may never result in illness. These new developments have brought a host of ethical and legal issues to the fore. For instance: what role (if any) should government play? Should it impose boundaries on PGD, or leave decisions in the hands of parents? Since the physical risks and discomforts associated with PGD are borne only by women, should testing be their decision alone or should partners play a decision-making role, too?

The current attention of many Western feminists has also shifted to moral issues linked to newer sex selection techniques. For a woman undergoing IVF, selecting embryos of the desired sex can easily be accomplished without further bodily intrusion (although at increased cost). Those who don't need to go through IVF can use sperm-sorting techniques to increase the chance of having a boy (it doesn't work as well for girls).⁴⁸ Regulations in some countries forbid PGD for social sex-selection, but in the U.S. commercial markets for sex-choice and sperm-sorting techniques proliferate unchecked by any regulation apart from laboratory certification and voluntary limitations set by service providers.⁴⁹ According to a

45 American College of Obstetricians and Gynecologists Practice Bulletin, Invasive Prenatal Testing for Aneuploidy, *Obstetrics and Gynecology* 110, 2007, 1459-67.

46 Public Law 100-374, 122 Stat. 4051 (Oct. 8, 2008).

47 Prenatal Testing and Disability: A Truce in the Culture Wars? *Hastings Center Report*, 39(3), 2009, 7-8.

48 LP: my understanding is that the reverse of this is true: sperm sorting is likely to be more successful when girls are sought.

49 MicroSort (<http://www.microsort.net>) whose principal clinic is in Fairfield, Virginia offers this service for a hefty fee to parents who already have at least one child and limit their selection to a child of the "nondominant" sex. Many parents from outside the U.S. are using this service, too. For more extensive critique, see Spar 2006, chapter 4. For a recent survey of sex selection preferences, see "Preconception sex selection demand and preferences in the

survey by The Genetics and Public Policy Center, most U.S. clinics that offer PGD have no policy against nonmedical sex selection and 42% have done it.⁵⁰ Some question the co-optation of MDs to perform procedures that offer no medical benefits. Those who stress unfettered patient choice often liken it to cosmetic surgery, but unlike cosmetic procedures sex-selection affects future persons and may have substantial social consequences.⁵¹ So medical organizations are divided. The American Society for Reproductive Medicine has lifted its former objections, but the American College of Obstetricians and Gynecologists continues to oppose the practice. They fear that such requests may ultimately support sexist practices.⁵²

Feminists are divided, too. When the only prenatal means to select for sex was amniocentesis or chorionic villi sampling followed by abortion, feminist-friendly scholars and activists hesitated to recommend legal prohibition of non-medical sex-selective abortion. They feared that such a policy would increase oversight of women's reproductive decisions and endanger reproductive rights. Preconception sex selection raises different moral issues than sex-selective abortion. Some think that sex selection may not be objectionable in itself and may actually enhance women's autonomy (Steinbock 2002, Zilberberg 2004). They note that studies of sperm-sorting have shown that more parents in the West select for girl children than boys. Others point to weaknesses in arguments that emphasize the preferences of parents over other considerations. They note the continuing preference of parents for a boy as their first child and cite data showing the greater assertiveness and higher achievement of first children. So if sperm sorting or other methods of sex selection were to become widespread, girl children would suffer gender discrimination disproportionately. Moreover, parents who invest substantial resources to get a girl child are likely to have a particular kind of girl in mind. A mother of a MicroSort baby was quoted as saying that she wanted a girl she could play Barbies with who had long hair and pink fingernails.⁵³ Of course, some parents may want a child of a specific sex for reasons that do not threaten the child's future autonomy or well-being, but many still find the practice of selecting the gender of one's offspring intensely disquieting.

United States," T. Jain et al., *Fertility and Sterility* 85(2), 2008, 468-473. The report indicates that only eight percent of couples would opt for the technique using currently available sperm sorting technology. The cost is about \$2,500 per cycle of intrauterine insemination. Often three to five cycles are required.

50 See www.washingtonpost.com, 9/27/06.

51 LP: Of course, so do other procedures that are not normally medically necessary, such as abortion. We need to be very careful to think very broadly about these issues having to do with appropriate medical involvement.

52 See the ACOG Committee Opinion: Sex Selection, No. 360, Feb. 2007 at www.acog.org/from_home/publications/ethics. Despite their objection, 42% of U.S. clinics doing PGD offer sex selection and 9% of PGD is for this purpose. Data are from a survey conducted by the Genetics and Public Policy Center available at <https://jscholarship.library.jhu.edu/handle/1774.2/842/browse> and summarized at www.washingtonpost.com, 9/21/06:A02.

53. Cited in Marcy Darnovsky, Revisiting Sex Selection, *Gene Watch* 17(1), 2004, 3-6.

Many find the new possibilities for shaping offspring in other ways equally disturbing. When the technology for testing embryos for single gene disorders such as Huntington's Disease was first developed, potential uses of these techniques seemed clear cut. PGD provided a means whereby couples at high risk of having a genetically-impaired child could achieve a healthy birth. Initially, the principle issues were technical, given the difficulties associated with carrying out genetic tests on single cell removed from three to five day embryos and the limited range of diseases that could be tested for. Today, tests are available for a rapidly increasing number of single gene disorders, and PGD has sparked more debate and controversy than perhaps any other area of reproductive or genetic medicine. Newspaper headlines about "designer babies" and "slippery slopes" every time a new development is announced. In some countries the use of PGD is more strictly regulated than any other prenatal tests (in the U.K., for instance). Differing national approaches to regulation have contributed to the growth of reproductive tourism. Many travel abroad for treatment when their home country prohibits a procedure.⁵⁴ Often, they come to the U.S., where about a majority of fertility clinics now offer PGD.⁵⁵

Analyses of the ethics of PGD inevitably rekindle debate about the 1920s negative eugenics movement in the U.S. and the subsequent Nazi "racial hygiene" program. That program borrowed from U.S. laws, but it extended eugenic measures to horrific levels far beyond the ambitions of even the most ardent eugenicists.⁵⁶ The nondirective model of genetics counseling that I have critiqued was shaped in part by reaction to those abuses, particularly the forced sterilization of those deemed unfit who were alleged to be "polluting" the gene pool. The state of Indiana (where I taught for two decades) was the first to institute a forced sterilization program in 1907 (they targeted "mental patients, prisoners, and paupers"). Twenty nine states eventually followed. In 1927 in its infamous *Buck v. Bell* decision, the U.S. Supreme Court upheld the constitutionality of mandatory sterilization laws. In all, 60,000 Americans were sterilized before the practice came to a halt in the 1970s.⁵⁷

Moral commentaries on PGD frequently allude to past eugenic practices. Those who oppose the technologies altogether often invoke slippery slope arguments that liken the new positive eugenics to the abuses perpetrated by such former social movements. Those who believe PGD should be used only for therapeutic purposes think they can prevent a slide down the slippery slope by limiting its use to disease

54. See for instance, [www. Washingtonpost.com](http://www.Washingtonpost.com), 6/14/06 and [www. Bionews.org](http://www.Bionews.org), 7/10/07.

55. The haste with which U.S. clinics scramble to offer PGD is not without a price. In a recent survey, 21% of clinics that offer PGD were "aware of" errors having been made including children born with a problem that was supposed to have been screened out. Data from a survey conducted by the Genetics and Public Policy Center available at <https://jscholarship.library.jhu.edu/handle/1774.2/842/browse>.

56 On the history of eugenics movements, see Diana Paul 1998 and Daniel Kevles 1985; LP: I wonder if it's even appropriate to call what the Nazis did "eugenics," just as it seems inaccurate to call the murder programs "euthanasia."

57 A researcher recently unearthed the report card of Carrie Buck, the subject of the Supreme Court case. She actually had normal intelligence! The story of her life is available at www.timesdispatch.com.

prevention. They point to the difference between the earlier state mandated negative eugenics that relied on state control to deny choice to individuals and present molecular genetic techniques where prospective parents have authority over embryo screening and selection. Some would extend liberal eugenic policies to allow parental authorization for nonmedical sex selection and enhancement of normal children's capacities. The authors of *From Chance to Choice* (Buchanan et al. 2002), for instance, maintain that improving children through bioengineering is not significantly different from improving them through education. They favor a policy that allows parents great latitude to choose the "best" embryos within a range that permits their children a reasonably "open future."⁵⁸ They would deny parental discretion, however, for such "self-defeating" enhancements as growth hormone treatment and memory enhancements but only because that would establish an "arms race." Everyone who stood to benefit and could bear the cost would compete for greater advantage. They focus on allowing free rein to the reproductive freedom of prospective parents and imposing limitations only to prevent demonstrable harms.⁵⁹

Buchanan and his fellow authors would also allow sex selection for nonmedical reasons as long as it does not exhibit systematic biases against women and give rise to injustices against them (184). Like most ethicists they deride sex-linked abortion as practiced in some parts of South and East Asia.⁶⁰ But they give considerable latitude to parents who use sex selection for "family balancing," for instance. They do not see such practices as morally problematic. Others who are not so sanguine about the harms that sex selective practices may bring about say if "family-balancing" is a good thing, why encourage people to balance families only for sex? Why not balance for race, too? Such criticism points to the exaggerated importance often ascribed to gender.

The latitude Buchanan and his fellow authors grant to parental discretion is a more subtle and sophisticated version of law professor John Robertson's individualistic defense of reproductive freedom

58. This phrase echoes Joel Feinberg's usage in his widely cited article "The child's right to an open future," 1980. Feinberg, however, did not have bioengineering in mind. The example he emphasized was from the 1972 Supreme Court decision, *Wisconsin v. Yoder*, which dealt with the practice of an Amish sect to withdraw their children from public school before they reached the permissible age for withdrawal. For an engrossing discussion of this and related issues, see Scott 2006.

59. For defense of this view, see M. Mameli, "Reproductive cloning, genetic engineering and the autonomy of the child: The moral agent and the open future," *JME Online* 2007, 33 87-93. Available at <http://wjme.bmj.com>. For a thought-provoking critique, including an intriguing interpretation of the notion of harm underlying the view of Buchanan, see Groenhout 2004. My own critique of Buchanan's perspective resembles hers though she focuses on deficiencies in the conception of justice offered and I stress inadequacies in the underlying understanding of autonomy (one facet of just-making considerations).

60. India is one of the few countries where males significantly out-number females. The increased prosperity of the Indian middle class has deepened this long-term trend, as ultrasound technology is used to perform sex-selective abortions. See www.globalfundforwomen.org, particularly their June 2007 bulletin. Note also Low male-to-female sex ratio of children born in India: National survey of 1-1 million households, www.lancet.com 367:1/21/06.

discussed in Chapter 4.⁶¹ It also has affinities with the stance of a number of utilitarian scholars such as Jonathan Glover, Derek Parfit (1984), John Harris (1992), and Julian Savulescu (2001). However, Savulescu's rendering of parental agency stretches further than any of the others. He characterizes his own position as "procreative beneficence." For him, it is not merely morally permissible for parents to select the "best" children they could have, given all the genetic information available to them, but a moral requirement that they do so. This stance has provoked severe criticism. What is to count as a "demonstrable harm"? Or as "best"?

Critics point out that no discrete individual is harmed by bringing to birth an impaired child rather than an unimpaired one. Savulescu rebuts this objection with the contention that continuing the pregnancy of a fetus likely to be disabled or selecting such an embryo causes "impersonal harm," because that choice makes the world a worse place than it needed to be.⁶² In succeeding articles he has tempered this claim with the proviso that it would not be appropriate to legally enforce this moral obligation. However, he and some other supporters of this position drift back and forth between life circumstances that should be proscribed, sometimes stipulating only lives that would be overwhelmed by suffering and other times including those that would face only deficits such as blindness, deafness, or spina bifida that are still compatible with a worthwhile and rewarding existence. Further implications of Savulescu's perspective for existing people who are either born with disabilities or acquire them later in life is particularly troublesome. Critics express concern that this position is likely to intensify discrimination against the disabled.

Many commentators wince at the claim that moral obligation can extend so far. Jonathon Glover calls the viewpoint that would morally require termination "procreative perfectionism." He fears that such a policy would overlook a variety of kinds of good life and favor some simplified version of the "best" life. He cautions that morally requiring potential parents to aim for the child with the best life prospects might put too great a burden on them (2006, 54). Michael Parker shares this concern. He argues that parental obligations involving the foreseeable lives of their future children are not suitably captured by Savulescu's model which oversimplifies the nature of decisions involving embryo manipulation and preconceptive sex selection.⁶³ These practices are personally complex and have weighty social and political ramifications.

Before discussing such objections in detail, I will mention an alternative rejoinder to Savulescu.⁶⁴ Rebecca Bennett contends that decisions about whether to transfer an embryo that carries a

61. For a comprehensive critique of ethical and legal issues in PGD (from the perspective of the British law) including discussion of Buchanan's perspective, see Scott 2006.

62. Savulescu and Guy Kahane, The moral obligation to create children with the best chance of the best life, *Bioethics* 23(5), 2009, 274-290.

63. M. Parker, The best possible child, *Journal of Medical Ethics* 2007; 33:279-283.

64. "The fallacy of the principle of procreative beneficence," *Bioethics* 23(5), 2009, 265-273.

genetic disorder or abort such a fetus are not *moral* choices at all but solely personal preferences. To argue the contrary, she insists, puts a lower value on the lives of disabled people and infringes the reproductive autonomy of parents by endorsing routine testing of embryos and fetuses. I share her objection to routine genetic testing, principally because of the coercive, autonomy-diminishing influence that I referred to. Nonetheless, I am not convinced that either Saveluscu's or Bennett's depictions of parental choice exhaust available options. Bennett is right, of course, that people who want to implant only a "normal" fetus or choose to discontinue the pregnancy of a fetus who tests positive for a disorder may make this choice for what they believe to be non-moral reasons. Perhaps they have negative attitudes toward people with disabilities or they can't afford the extra cost of care. However, though lack of support services or the steep price of care might *excuse* such conduct, that doesn't exempt it from moral assessment. Of course, some do see themselves as making a *morally* weighty decision. They apparently have a different hierarchy of moral values than those who voluntarily undertake genetic selection or termination. If given a choice about prenatal testing they are likely to turn it down or, if they do consent, to say that it is only to be prepared for bad news. Viewed objectively, the moral value of prospective parents' decisions does not depend on their subjective attitude any more than racism or sexism would depend on the subjective attitude of the person accused of discrimination. Though I share Bennett's concern that Savulescu's stance devalues the life of disabled people, I am not convinced that his categorization of these choices as morally significant is mistaken or that the reproductive autonomy of these prospective parents is compromised by others' views about the morality of their decision unless obstructions are put in their way. 65

Michael Sandel elaborates a view on genetic modification that contrasts sharply with all of the positions I have characterized so far. In *The Case against Perfection* (2007) he contends that intrusions into the genetic makeup of children violate human nature and the sense that a child is a gift. Arguing in a vein reminiscent of Paul Ramsey and Leon Kass (Chapter Three), he acknowledges that his gift language has religious overtones but contends that it has everyday uses, too---"A gift for piano playing," for instance. Such examples don't completely resolve my own reservations about the use of gift language whether to support genetic intervention (as in "The Gift") or to oppose it. However, I share Sandel's suspicion that choices made in the marketplace of genetic characteristics may not be fully reflective choices. But unlike him, I don't think they are mere impulses, either. Considering the lengthy, costly, and intrusive process that genetic intervention requires, couples have ample opportunity to weigh their decision carefully. However, like many other major expenditures, commercial exploitation often impedes autonomous decision-making. Sandel's position incorporates other weaknesses, too. Referring to liberal eugenicists, he alleges that since they impose no constraint on permissible enhancements as long as they respect a child's right to an open future and promote well-being, enhancements may become morally obligatory and enforceable by the state. This is a frightening prospect but unlikely since parents are not presently legally required to promote their children's well-being beyond certain specific policies such as vaccination, newborn screening, and school attendance.

65. LP AD notes that the last part of the paragraph should be simplified. I have put it here as it is in her manuscript, however, as I find it hard to understand and don't want to misrepresent her position.

Sandel has another objection to liberal eugenics which I think is far more persuasive. He notes that attempts to eliminate chance from baby-making and bring it wholly within parental control ignores the contingency of human life. It is this contingency that motivates social solidarity and provides the social context for the view of personal autonomy I have developed here. Taking on so much responsibility for the personal destiny of one's children potentially diminishes the sense of solidarity with society's less fortunate members—those who lack the material resources to utilize all the techniques of enhancement that the marketplace provides. Despite our efforts to tinker with the genetic makeup of our offspring, we cannot remove the unpredictability of life. Hard as some might work to bring the characteristics of their children within their own control, parenthood is bound to bring surprises, often unbidden. The illusion that elimination of life's chanciness lies within the power of individuals one by one (or two by two) isolates us from one another and creates a false sense that we are responsible only for ourselves, thereby obscuring obligations owed to others, both close and distant, who have enabled us to survive and thrive. Human interdependence is inextricably tied to the nature and social lotteries. If everyone with the economic means were to elect genetic selection, resources allocated to other human needs would shrink, further diminishing social solidarity. Considering the substantial costs associated with IVF, PGD, and sperm sorting, this is a significant consideration.

The solidarity-diminishing influence of genetic selection techniques has been addressed most vigorously by disability advocates. They have raised objections to all uses of genetic selection including abortion for reasons of disability.⁶⁶ These practices, they claim, send the wrong message, that the lives of disabled people aren't worth living (Saxton 1998). Some disability advocates frame the issue more starkly: the new genetics is being used to prevent people like themselves from being born (Shakespeare 1999, Wendell 1996). But many supporters of abortion rights think that prohibiting abortion because a child will be susceptible to a disability raises the same issue as prohibition for selection of a child's sex. Requiring women to justify their abortion decisions and limiting permissible grounds for abortion put all women's reproductive freedom in jeopardy. In response, some disability scholars have sought to draw a principled distinction between abortion because the fetus will be born disabled and abortion for other reasons (Asch 1996). But considering the manifold reasons a woman might have for aborting a fetus other than a belief that its life wouldn't be worth living, it is difficult to make a hard and fast distinction.⁶⁷

Yet the concerns of the disability community cannot be disregarded. Many people with disabilities live long, rewarding, and satisfying lives. And disability scholars are undoubtedly right that

66. Some, however, selectively support extending options currently available to parents of deaf children (Letting the deaf be deaf: Reconsidering the use of cochlear implants for prelingually deaf children," Robert A. Crouch in *Hastings Center Report* 27(4), 1997: 14-21. They would like to use genetic selection to insure that the child and deaf parents will also be deaf (or that parents with very short stature will have a child like them). Members of the Deaf community argue that deafness is not a disability but a cultural identity. A recent survey of PGD clinics in the U.S. found that 3% reported having intentionally used PGD "to select an embryo for the presence of disability." *NY Times* 12/5/06, D5. Under the terms of the 2008 amendments to the British HFEA (see Ch. 2), the deliberate creation of a child with a disability is prohibited. See www.timesonline.co.uk 2/24/08 for further details.

67. James Lindemann Nelson (2003), Ch. 1) rehearses many of the reasons a woman might make this choice.

major problems of disability are often not biological but social, due to individual attitudes and institutional practices that impeded disabled people's access to services that the able-bodied often take for granted (Asch 1989, Parens and Asch 1999).⁶⁸ Besides, no one knows when they might need disability services. For disability arises from many conditions. Efforts to forestall disability through genetic selection may very well diminish support not only for those who suffer from genetic anomalies but also for those who become disabled through the effects of aging or chance accidents that may befall any of the currently able-bodied.⁶⁹

Awareness of the inevitable contingency of human life does not resolve all the quandaries that the

[LP: This section on eugenics ends rather suddenly here, and I have not found any further material on it in the various drafts and scans to which I have access from AD's computer.]

Conclusion

I have sought to show how adherence to an individualistic model of autonomy hampers effective medical decision-making, gives insufficient attention to the impact of decisions on family members, undermines the agency of those who are excluded from the decision-making process, and often imposes unjust burdens in those affected by others decisions. Uncritical advocacy of this model by bioethicists fosters what Susan Wolf calls a "bioethics for the privileged," serving the interests of those who have ready access to health care and an understanding physician who respects them (1996, 18). Medical practitioners who recognize limitations of the dominant model may modify their procedures to draw into discussion other family members centrally affected by a decision. But these efforts are seldom incorporated within a systematic policy. They tend to be fragmentary and *ad hoc*, often inadvertently polarizing family conflict and jeopardizing the well-being and autonomy of those most centrally affected. And they are only rarely supported by institutional structures. Without major reconfiguration of structural patterns, rearrangement of individual provider-patient relationships can have little effect.

As employed within clinical medicine and integrated into clinical practice, then, personal autonomy needs to be understood as involving situated social beings positioned relationally, both to their families and intimates and to the practitioners who care for them. Two major reorientations are critical to implementing such a model. First, all parties must be envisaged within the institutional contexts that

68. I suspect that AD is referring here to Erik Parens and Adrienne Asch (eds.), *Prenatal Testing and Disability Rights* (Washington, DC: Georgetown University Press, 2000).

69 LP: For a different perspective on many of these issues, see, among other papers, my review of Parens and Asch in *Social Theory and Practice*, 27(4), October 2001: 681-687, and Loving Future People, *Reproduction, Ethics and the Law*, ed. Joan Callahan (Bloomington: Indiana University Press, 1995).

circumscribe their options. Such a shift in perspective would bring into focus the injustices suffered by those who bear disproportionate burdens. Decision-making strategies limited to balancing interests among individual family members risk silencing the voices of those most immediately affected. Such persons need the protection that can only be provided by a well-crafted formulation of the principle of autonomy and an unswerving commitment to honor it.

Second, reorientation needs to be structured in ways that recognize and respond to injustices within personal relationships, both injustices central to institutional structures and those which are tangential. I have alluded to strategies that provide occasion for all family members to articulate their own perspectives and air their disagreements before any decision is imposed. Such an approach would create space within which their concerns could be heard both separately and collectively. But to avoid reinscribing injustice in a new guise, a relational model would need to take full account of relevant ways in which individuals and families are differently situated in relation to one another and to health care resources. For such an approach to be effective, providers would need to be more sensitive to family dynamics, recognize situations where the voices of the less powerful are silenced, and intervene in ways that facilitate their active participation in decision-making processes. Implementation of such a strategy would impose increased demands on health care systems that are only belatedly (and slowly) casting off their paternalistic legacy and minimally recognizing individual autonomy. To aim for less, though, would be to acquiesce in social arrangements that perpetuate disparate measures of respect for the privileged and the vulnerable.

Few of the issues that arise within the context of genetic disease are unique to these circumstances. Supporters have claimed that The Human Genome Initiative has spawned only one novel moral topic: the issue of ownership of one's genome and control over the use of information about it.⁷⁰ Though this claim is disputable, assent would not diminish the intensity, urgency, and gravity of issues that spill over from other contexts. Hopefully, addressing them where they arise most starkly will illumine other contexts too. For the dominant conception of autonomy that assumes relationship to others is only contingently connected to one's own identity has a distorting influence in many health care settings, particularly when decisions involve the very young, the very old, the infirm, and the chronically ill.⁷¹ The need for a relational understanding of autonomy is evident in a broad array of situations.

NOTE

I wish to express my gratitude to those who contributed to my education in clinical genetics: the Indiana University Study in a Second Discipline Program that enabled me to devote an entire semester to the study of clinical genetics and particularly to Dr. David Weaver's patient mentoring. Thanks are due too

70. Alex Capron makes this observation, 1990. It is supported by the authors of the British Clothier Report, 1992.

71. A number of feminist authors have addressed this issue. See, particularly, the publications of Susan Sherwin, and McLeod and Sherwin 2000.

to Dr. Ellen Solomon and her colleagues in the Division of Medical and Molecular Genetics at Guy's Hospital, University of London who so generously gave their time to me, so I could compare the delivery of genetic services in the US and UK. My gratitude also to Catriona MacKenzie and Natalie Stoljar for their careful and insightful comments on portions of this chapter which appeared in the 2000 volume they edited, to Helen Bequeart Holmes whose comprehensive understanding of genetic issues enriched my own, and to Edmund F. Byrne whose comments on previous drafts helped me to say what I meant. Remaining inadequacies are, of course, my own.